

UNIVERSITY OF CALIFORNIA LOS ANGELES

ASSENT TO PARTICIPATE IN TISSUE BANKING

Research Title: Rare Brain Disease Tissue Bank

1. My name is Gary W. Mathern, MD. I am a brain surgeon.
2. We are asking you to take part in a research study because we are trying to learn more about your rare brain disease by collecting your blood, brain fluid, saliva and tissue left over after your brain surgery and storing them for research. I want to understand what causes your disease. I will keep your brain tissue for a long time.
3. If you agree to be in this study you do not have to do anything other than agree to have your *left over* brain tissue, brain fluid, blood and saliva stored in the Rare Brian Disease Tissue Bank for research studies and to share that information with other people studying rare brain diseases.
4. We will be using brain tissue that is left over from your brain surgery. The amount of tissue removed will not be increased for this research. The blood, brain fluid and saliva that we use will be gathered while you are under anesthesia during your surgery. Your participation in tissue banking will not cause any additional risks or discomfort other than what you would normally experience as part of your surgery.
5. Participation in tissue banking will not help you directly but may help people in the future who have similar rare brain diseases.
6. Please talk this over with your parents before you decide whether or not to participate. We will also ask your parents to give their permission for you to take part in this study. But even if your parents say öyesö you can still decide not to do this.
7. If you donö want to be in this study, you donö have to participate. Remember, being in this study is up to you and no one will be upset if you donö want to participate or even if you change your mind later and want to stop.
8. You can ask any questions that you have about the study. If you have a question later that you didnö think of now, you can call me at 310-825-7961 or ask me next time.
9. Signing your name at the bottom means that you agree to be in this study. Your doctors will continue to treat you whether or not you participate in tissue banking. You and your parents will be given a copy of this form after you have signed it.

\_\_\_\_\_  
Name of Subject

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date